

DOCUMENT RESUME

ED 320 338

EC 231 146

AUTHOR Lowenthal, Barbara; And Others
TITLE The Special Educator and the Hospital Ethics Committee.
PUB DATE Feb 90
NOTE 40p.; Paper presented at the Conference of the Learning Disabilities Association (Anaheim, CA, February 21-24, 1990).
PUB TYPE Reports - Descriptive (141)
EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS *Advisory Committees; *Bioethics; Case Studies; Child Abuse; Consultants; Death; Family Problems; *Hospitalized Children; Hospitals; Infants; Medical Care Evaluation; Medical Services; Neonates; *Severe Disabilities; *Special Education Teachers; Teacher Role; Technology
IDENTIFIERS *Education of the Handicapped Act Amendments 1986; Euthanasia; *Hospital Ethics Committees

ABSTRACT

With the advent of Public Law 99-457, special educators may be expected to observe and/or serve on Hospital Ethics Committees (HECs) in order to better assist families who have seriously ill and handicapped infants and children. Issues considered by such committees include alternative viewpoints on infant euthanasia and their right to life, the provisions of current child abuse legislation, and possible effects on families. This article discusses HECs and the issues with which these committees grapple. The paper describes the HEC in one large, metropolitan/suburban hospital. Additional issues reviewed in the context of biomedical technology are withholding versus withdrawing treatment, experimental therapy, brain death in infants, technology and the prolongation of dying, and infant donors. It suggests some guidelines to assist in the training of special educators for serving on or supporting these committees, such as having special education students observe an HEC and provide respite care to families of infants and children with severe handicaps. The paper concludes with four case histories which exemplify the complexity of the issues and allow the reader to consider the issues presented within the context of the reader's personal values and opinions. Contains 34 references. (DB)

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The Special Educator and the
Hospital Ethics Committee

Prepared by

Barbara Lowenthal, Ed.D., Associate Professor
Northeastern Illinois University
Department of Special Education
5500 North St. Louis Avenue
Chicago, IL 60625
312/583-4050

Marjorie Getz, Ph.D., Educational Specialist
David Sheftel, M.D., Director of Neonatal Follow-Up
Seymour Metrick, M.D., Chairman
Lutheran General Hospital
Division of Pediatrics
1875 W. Dempster, Suite 335
Park Ridge, IL 60068
312/696-8610

Celia Kaye, M.D., Ph.D., Geneticist
(Formerly of Lutheran General Hospital)
Department of Pediatrics
University of Texas Health
Science Center at San Antonio
7703 Floyd Curl Drive
San Antonio, TX 78284

Paper presented at the Conference of the Learning Disabilities Association
(Anaheim, CA, February 21-24, 1990).

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Barbara
Lowenthal

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Abstract

With the advent of Public Law (P.L.) 99-457, special educators may be expected to observe and/or serve on Hospital Ethics Committees (HECs) in order to better assist families who have seriously ill and handicapped infants and children. The educator, to fulfill provisions of the new legislation, needs to be aware of some of the issues that could be considered by the Committees. These issues include alternative viewpoints on infant euthanasia and the right to life, the provisions of current child abuse legislation, and possible effects on families. This article discusses the Hospital Ethics Committee, the issues with which these committees grapple, suggests some guidelines which may assist in the training of special educators for serving on or supporting these committees and concludes with case histories which exemplify the complexity of the issues and allow the reader the opportunity to apply the issues presented within the context of the reader's personal values and opinions.

The Special Educator and
the Hospital Bioethics Committee

In 1983 the Federal Department of Health and Human Services (HHS) promulgated rules and reporting procedures, involving immediate intervention by the government, regarding alleged denial of medical treatments to handicapped newborns. The now famous "Baby Jane Doe" case provided the impetus for these rules; in this case parents refused surgical closure of their infant daughter's spina bifida, with the infant's death imminent, secondary to infection. Then President Reagan and his Administration argued that Section 504 of the Rehabilitation Act of 1973, which prohibits discrimination against handicapped people by programs receiving federal funds, provided the basis for the Department of HHS rules and government intervention in this and similar cases.

During the few months these original rules were in effect there were many examples which demonstrated the excessive intrusiveness of the HHS rules relative to patient confidentiality and medical treatment. The American Academy of Pediatrics (AAP) took an active role in striking these rules (American Academy of Pediatrics v. Heckler, 1983).

In January of 1984 HHS promulgated the final "Baby Doe" rules regarding treatment for disabled infants, effective February of 1984. These revised Baby Doe rules mandated the posting of a notice visible only to hospital employees (rather than posted in a public arena, as first required) stating hospital and/or federal policies prohibiting discrimination against handicapped infants. It was mandated that these signs be 5" X 7" (as opposed to the 14" X 17" originally required). It was requested that the notice delineate a hierarchy of reporting procedures, with alleged violations to be reported first to the Hospital Ethics Committee (HEC) (if established and operational), followed by reporting to the state child protection agency;

the federal government was delineated as contact of last resort (rather than first contact as in the original rules). The new "Baby Doe" regulations, therefore, required state child protective agencies to establish methods of assuring that they use their full authority to prevent unlawful medical neglect of minor children. In the legislation medical neglect was defined as "withholding of medically indicated treatment from disabled infants with life-threatening conditions." Therefore the withholding of needed medical care would constitute medical neglect, which would constitute child abuse or neglect, and call for legal action by the state protective agencies.

In 1984, Congress modified the child abuse and neglect legislation to empower the states to prevent medical neglect of newborn babies (U.S. Child Abuse and Treatment Amendments, 1984). According to these Amendments, treatment may be terminated only when in the physician's reasonable medical judgment, it merely prolongs the process of dying (Gustaitis, 1988). The law does not mandate that interventions should end because the infant has a right not to be subjected to painful treatment with little hope of subsequent recovery. The language of the Child Abuse Amendments of 1984 appears to be fairly specific that the only consideration about which to make a decision about the treatment of seriously ill/handicapped neonates is medical efficacy. The future quality of the child's life is not to be an issue. The only definitions of best interest for the baby would be those that are served by treatments that would preserve life, regardless of the outcome for the infant and the family (Weil, 1987, Stevenson, Ariagno, Kutner, Raffin, & Young, 1986). This has become identified as the "best interest" standard. One exception to this dictate in the Child Abuse Amendments is the following: treatment does not have to be provided if "such treatment would be virtually futile in terms of the survival of the infant, and the treatment itself under such circumstances would be inhumane" (Weil, 1987, p. 90).

The revised "Baby Doe" regulations also encouraged (but did not require) hospitals to establish HECs. These in-hospital committees were to be established in order to develop and implement policies designed to protect the rights of hospitalized minors, as well as to serve as a forum for discussion of complex cases where the withholding or withdrawal of life-sustaining medical treatment is being considered. The American Academy of Pediatrics, dedicated to ensuring that all children receive the most appropriate medical care, described the provision of voluntary establishment of HECs as "the most important element in the new rules" (Wehrle, letter to AAP fellows, February 7, 1984).

HECs consist of individuals congregated to consider complex issues of medical treatment for children. Professionals involved in the treatment and education of children and adults with disabilities can make a substantial contribution to the HEC, either as committee members or serving in a supportive capacity to families involved in an HEC discussion. This article is intended to accomplish the following purposes: examine Public Law 99-457 in relation to professional responsibilities and the HEC; discuss the controversial issues involved in withholding or withdrawing treatment from a severely disabled pediatric patient; describe an established HEC; and allow the reader to engage in an exercise of applying the information presented by examining several fictitious case histories so that the reader can experience the complexity of the issues and begin the process of self-exploration which these issues demand.

Public Law 99-457: Unique Poles for Special Educators

Public Law (P.L.) 99-457 was passed by Congress in October of 1986, and amends the Education of the Handicapped Act (P.L. 94-142), passed by Congress in November of 1975. P.L. 99-457 authorizes service delivery consistent with

research findings accumulated since the passage of P.L. 94-142. Specifically P.L. 99-457, Part H, provides more services, earlier, to young handicapped children and their families. A wide range of family services and variations in programming, allowing for diversity in family needs, are encouraged. Instead of the Individual Educational Program (IEP) developed by the multidisciplinary team serving the school-aged child, P.L. 99-457 stipulates that an Individual Family Service Plan (IFSP) be developed by the case manager with the family rather than for the individual child, thereby encouraging the perspective of family-based intervention.

The variety and extent of family-based intervention needs have been influenced by dramatic advances in biomedical knowledge and technology. It is now possible to sustain and treat newborns, especially those of low birthweight, who, not long ago would have died after birth (Getz-Sheftel, 1982; Raye & Healy, 1984). Many of the survivors either have established or are at risk for adverse developmental sequela; many survive their neonatal period with congenital disorders which, until recently, were incompatible with life. For example, according to the most recent data, about 3 to 5 percent of babies born in the United States who weigh less than 3 1/2 pounds have congenital anomalies and other handicaps (Szanton, 1986). Ironically the use of modern technology has helped these infants survive but has also led to conflicts over the fate of those neonates who are profoundly impaired. The "Baby Doe" case is just one of several documented (within a sea of undocumented) cases in which it has been argued that life-prolonging or life-enabling treatment should be discontinued for neonates who are disabled and/or suspected of being severely mentally impaired.

Beginning in the 1990-1991 school year, P.L. 99-457 extends P.L. 99-142 to mandate a free, appropriate public education to all American children, ages

3-21. Furthermore, P.L. 99-457 created a new state grant program for handicapped infants and toddlers (birth through age 2). Therefore children with complicated medical conditions are on the legal threshold of the nation's early intervention and public-school programs. Accordingly, it is likely that the complex question of withholding or withdrawing medical treatment will be raised on behalf of children enrolled in birth through 21 programs. Special educators and other professionals working within early intervention and public school programs may be called upon by the HEC and/or the family to observe or serve on a hospital ethics committee (HEC). Familiarity with the purposes and functioning of the HEC and the issues under consideration, as well as reflecting on one's own and personal values, are necessary preparation for making a valuable contribution to the HEC and assisting parents.

Issues: Infant Euthanasia v. The Sanctity of Life

Ethics is the branch of philosophy which deals with "right acting." There are two predominant principles within medical ethics. The principle of beneficence instructs the physician to do good; medical treatment provided to the patient must be for the good of the patient. The principle of maleficence instructs the physician to avoid doing harm; medical treatment must not harm the patient. The physician has ethical obligations to preserve the health and life of the patient. Children, and infants in particular, cannot provide guidelines as to the limits of their medical treatment. Consequently, HECs must look to the body of opinions regarding medical treatment, divided into two factions.

Infant Euthanasia

An issue for the HEC may be to consider the criteria for continuing treatment in the best interests of the child. In discussing this concern, some medical professionals (Duff & Campbell, 1973; Brandt, 1978) have argued

that there could be essential reasons for considering withdrawal of treatment and infant euthanasia. Their argument is that the use of medical technology can, in certain cases, increase the suffering of the infants. They feel that there may be instances in which life-prolonging treatment should be discontinued for severely ill and handicapped neonates. Consequently, they emphasize that infant euthanasia be an option when treating profoundly impaired infants.

A medical dictionary defines euthanasia as "1. A quiet, painless death. 2. The intentional putting to death by artificial means of persons with incurable or painful disease." (Stedmans, 1972, p. 439). Twycross (1977) further delineates euthanasia:

Voluntary euthanasia (is) requested by the sufferer (and) has been described as assisted suicide or homicide by request.

Compulsory euthanasia implies a decision by society or by an individual to end the life of a sufferer who cannot signify volition, for example, the severely handicapped infant and the demented.

Passive euthanasia (a more recent term) is withholding certain medical treatment intended to lengthen the lives of the incurably sick, in other words, letting nature take its course. (p. 128)

The "Baby Doe" regulations were a response to recent acts of passive euthanasia, practiced upon severely disabled neonates and children by methods involving either withholding treatment or life-sustaining sustenance or withdrawing treatment after a period of providing and monitoring the treatment. One study examined deaths occurring in a newborn intensive care unit from July, 1970 to June, 1972 and of the 299 deaths reported, 43 deaths (14%) resulted from the withholding or withdrawal of treatment (Duff & Campbell, 1973). The medical conditions associated with the deaths were as

follows: multiple anomalies (15); trisomy (8); cardiopulmonary (8); meningomyelocele (7); other central nervous system defects (3); and short-bowel syndrome (2). Robertson, evaluating several sources of data of medical practices with disabled neonates, concluded: "nontreatment of defective infants, now occurring in hospitals throughout the United States and England, is rapidly gaining status as 'good medical practice'" (p. 140).

A philosophical basis for the argument for nontreatment or withdrawal of treatment for profoundly impaired infants is given by Veatch (1976, 1978), Engelhardt (1975), and Jonsen and Garland (1976). Veatch (1978) begins with the principle that competent individuals who are terminally ill or otherwise profoundly disabled have the right to refuse life-sustaining treatment. Then, with great caution, Veatch argues that it could be morally acceptable for one person to refuse life-prolonging treatment for another individual who is not competent to make a decision. In this case it would be for a neonate, as long as the reasons for refusal would be in the best interest of the infant. Thus, from Veatch's perspective, the medical professionals who provide intensive care, the parents, or other possible decisionmakers, such as the HEC, must make every attempt to view the situation from the infant's perspective and to try to determine whether the future life of the infant could be so bleak that a competent person would refuse further life sustaining treatment.

For Veatch (1976), two factors would meet this criteria. First, the treatment must be likely to prolong life but not to correct the underlying condition that is responsible for the abysmal quality of the infant's continued existence. For example, treatment might cure a life-threatening infection in the baby but not correct a severely disabling anomaly. The second factor is that all objections to the future quality of life must be strictly patient-centered. These objections should not be confused with the

desires of others, such as perhaps the family or state, who do not want to assume the burdens of providing for the severely disabled baby's needs. A similar position has been proposed by Engelhardt (1975) who believes that decisionmakers have a duty to allow an infant to die if he/she would likely experience a short life of intolerable pain. This argument has been elaborated on by Jonsen and Garland (1976), who have stated it would be doing harm to the baby if technological interventions kept him/her alive only to live a life cut off to social intercourse or doomed to intractable pain and inevitable death during infancy. To give added weight to these philosophical points of view, a survey of pediatricians and pediatric surgeons was conducted in 1977 (Shaw); in this survey, 8270 of the respondents indicated they believed that not every newborn infant should be saved regardless of the circumstances. Physicians do not want to prolong the suffering of an incurably ill newborn; yet, they are dedicated to helping babies survive (Fackelmann, 1986).

According to Walters (1986), there may be two types of cases in which some health care professionals are inclined to advocate infant euthanasia in what they see as the best interests of the child. The first case is when there is evidence that the infant will die very soon anyway, no matter what is done. In this case medical treatment would serve only to prolong the newborn's death and therefore the extraordinary treatment should not be initiated. The second case is when the neonate can be served but only with heroic efforts. If nothing is done, the infant will likely die soon. However, if heroic treatment is initiated, the baby might be able to live indefinitely. Severe financial and emotional burdens may result which perhaps could then significantly affect the child's quality of life. These cases highlight the following concern: when considering the best interests of the baby, how can

healthy adults with no experience of disabilities imagine the quality and value of relationships a severely handicapped baby might have in what may or may not be a short term of life remaining to the child (Walters, 1986)?

Arguments for Treatment: Sanctity of Life

Underlying Walters' difficult question is the issue of the sanctity and right to life (Singer, 1983). Ramsey (1979) has vigorously defended the individual infant's right to life. The right to life is offered as the primary reason to provide necessary medical care irrespective of quality of life judgments. Ramsey states, "life is not a good; it is an inexplicable gift" (p. 207). Unless the individual's right is universal and independent of quality of life considerations, then our whole society loses its reason for defending only life except by the rule of "might makes right." In fact, the defense of a universal, unqualified right to life brings security and order within our society. Without this universal right, society must logically be viewed as a meeting ground for the "war of all against all" (Ramsey, 1978, p. 205). According to Powell, Aiken, and Smylie (1982), this individual right to life is superordinate to the interests of society. Thus, infants with severe disabilities have natural rights to existence which would be independent of the effect their life would have on society.

In a similar vein, Fletcher (1980) argues against the withdrawal of treatment from seriously ill neonates because it threatens to undermine the commitment of parents to provide necessary care and support for their children. According to Erikson's developmental theory, Fletcher notes that children must be able to trust their parents and their world. It is therefore important that strong societal support be maintained to encourage parental dedication to raising their children. Society then has a definite interest in seeing that parents and medical professionals provide whatever is needed to

support the lives of profoundly impaired/ill neonates, regardless of their quality of existence.

Fletcher feels that the inherent dignity of our society depends upon the manner that we care for and treat newborns with severe handicaps. He has made the following statement.

If we choose to be shaped by Judeo-Christian visions of the "createdness" of life within which every creature bears the image of god, we ought to care for the defective newborn as if our relation with the creator depended on the outcome. If we choose to be shaped by visions of the inherent dignity of each member of the human family, no matter what his or her predicament, we ought to care for this defenseless person as if the basis of our own dignity depended on the outcome (p. 205).

Other points made regarding the sanctity of life issue relate to the determination of exactly what constitutes a rewarding, self-fulfilling quality of life (Buess, Dussault, Brown, Mulligan, Orellove, Comegys, Rues, 1984). There is a tendency to impose society's standards on people with profound handicaps who may perceive the world in a different way and presume, therefore, that because a certain way of life or thinking may not be available or possible for the disabled individual that, by comparison, the quality of life for the disabled individual is so negatively affected, that, in effect, life is not worth living. Gunzburg (1981) expounds upon the arrogance of the "poor quality of life" argument for nontreatment:

Making the pronouncement that a multiply handicapped baby will not be able to live a happy contented life because he will not have neither now nor in the future, those things that decisionmakers consider to be vital for themselves and their children, is presumptuous thinking

which does not allow for the existence of other modes of thinking (p. 46).

The meaning of life could be different for the child who has profound disabilities. Sometimes, people with severe handicaps are exempted from the difficulties of participating in society. For example, a severely retarded person may not worry about nuclear war, pollution of the environment or income taxes. The quality of life issue is in many ways an indictment of society's attitudes toward individuals who are handicapped. The decision to withhold treatment to infants with severe handicaps can be based on the viewing of them as a commodity which limits our resources in our society. The Office of Technology Assessment of the United States Congress completed an analysis of the cost effectiveness of the technology in the neonatal intensive care units (NICUs) (Budetti, McManus, Barrand, & Heinen, 1981). They noted that while babies were surviving who, without the technology and care of the NICUs, would have died, they also note that in 1976, in economic terms, the cost effectiveness of facilitating the survival was questioned because the rate of survivors with severely handicapping conditions was doubled and consumption outweighed the productive potential of the abnormal survivor. However, as noted by Smith (1974):

The error we want to avoid is the notion that we should solve our limited resource problem simply by assessing the quality of the output. Such an approach leads one to think that the ideal result is either a "perfect" baby or a "dead" baby (p. 46).

There is another issue that may be of concern for the HEC in this argument for the sanctity and the right of life. In contrast to the accepted role of the health care professional to safeguard the sanctity of life in the interests of the older child, the situation with a premature, profoundly

handicapped neonate could be different (Weil, 1987). At an intellectual level, many professionals believe that the neonate is the moral equivalent of a child and is entitled to similar rights of life and protection. However, in actual practice there has been somewhat of a tendency to view the newborn, especially one with very low birthweight and a grave prognosis, to be less of a person than the older child. As a result, at least up until recently, some health care professionals have been willing to let parents decide whether to withhold or withdraw life-saving therapy if the baby's prognosis is very uncertain, especially if profound handicaps exist (Weil, 1987). As an example in 1982, in the case of "Baby Doe," the parents refused to give permission for their infant, born with Down syndrome and tracheoesophageal atresia, to have life-saving surgery (Ross, 1986). The U.S. government became involved in this case. Governmental intervention was consistent with a preponderance of case law which repeatedly ruled that while parents have basic and fundamental rights associated with raising their children, parents' rights are not absolute and that the rights of the child must also be recognized.

Another issue that may be considered by the HEC, which the special educator should be aware of, is the possible effect on the family of caring for a seriously impaired infant and how this may impinge on the future quality of life for the baby. On one hand, the parents may insist on continued treatment, although the physician feels this to be futile and may cause unjustifiable suffering of the baby (Baltimore Sun, 1986). The guiding principle for the physician is to do no harm; this principle may oblige the doctor to stop treatment against the parents' wishes. On the other hand, some parents may wish less aggressive treatment for the infant. The birth of a severely damaged or malformed infant could cause devastating emotional, financial, and social problems beyond the resources available to the family

(Harrison, 1986). As an example, results of a study of stress and concerns of families and handicapped children (Moore, Hamerlynck, Barsh, Spiker, & Jones, 1982) indicated that the severity of the child's disability was a significant predictor both of family problems and amount of stress. The conclusions of this study indicated that this relationship was due to the very real demands on the primary caretaker in caring for the disabled baby or older child. These findings are similar to those reported by Breslow, Saruch, and Mortimer (1982), who investigated psychological stress in mothers of severely disabled children. These researchers found that the more dependent the child is on others for daily activities, the greater the caretaker's distress.

Beckman-Bell (1980) also examined the relationship between specific characteristics of infants with severe handicaps and the number of parent and family problems reported by caretakers. High levels of stress were associated with the following infant characteristics: slower rate of progress, more difficult temperament, less social responsiveness, and the presence of unusual or additional caregiving demands. According to Seligman (1979), these studies provide some evidence that the severely handicapped baby may place significant stress in the family unit. In addition, the cost of intensive care could be financially overwhelming. Newborns with low birthweight can have hospital bills of \$1,000 a day in intensive care units with only a portion paid by Medicaid (Walters, 1986).

It may be of special significance for the HEC professionals to give information as soon as possible to the family about the following concerns: the type of medical treatment and special care that the baby might need, the community resources that can be of assistance, the financial responsibility that the family might incur, the respite care that would be available, the parent groups that can be of assistance, and the services that can be provided

under existing laws. An essential role for the educator can be to empower the family with skills, knowledge, and competencies that give them control over these resources that can meet their needs (Dunst, 1985). Thus, the special educator, if possible, can make a contribution here in assisting the family and the social workers on the HEC by having ready a current list of resources for the family including those individuals, professionals, and government organizations who can help them in their long term care of the seriously ill baby.

The conclusion of the President's Commission for the Study of Ethical Problems represents important information for special educators inasmuch as ways are suggested for the HEC to improve initial decisions and assure appropriate care of the seriously handicapped/ill newborn (Ray & Healey, 1984, p. 79-81). A selected summary of these conclusions is as follows:

- a. Parents should be surrogates for a seriously ill newborn unless they are disqualified by decision making incapacity, or unresolvable disagreement between them, or their choice of action that is clearly against the neonate's best interests.
- b. Decisionmakers should have access to the most up-to-date information as they consider individual cases. The significance of the diagnosis and the prognosis under each treatment option must be conveyed to the parents.
- c. Hospitals should have clear policies that require prospective or retrospective review of decisions when life-sustaining treatment for the infant is withheld or when parents and providers disagree about the correct decision for the infant. The best interests of the infant should be pursued when those interests are clear. The policies should allow for the exercise of parents discretion when a child's interests are ambiguous.

Hospital Bioethics Committee:

Lutheran General Hospital, Park Ridge, Illinois

This portion of the paper describes the Hospital Ethics Committee in a large, metropolitan/suburban hospital. All of the authors of this paper have either served on, presented cases to, or observed this HEC.

The following background information is offered about the hospital. Lutheran General Hospital (LGH) is a not-for-profit, licensed 713 bed, tertiary care, teaching, research, and referral hospital, located in Park Ridge, Illinois, a northwest suburb of Chicago. It is affiliated with the Lutheran General Health Care System and the University of Illinois; the majority of departments have residency and fellowship programs. The Lutheran General Children's Medical Center (LGCMC) provides care to in-patients and out-patients per year. Care is provided by 76 attendings, with subspecialists in the areas of adolescent medicine, ambulatory pediatrics, anesthesiology, cardiology, emergency room medicine, endocrinology, hematology/oncology, infectious diseases, intensive/critical care, gastroenterology, genetics, pulmonology, neonatology, neurology, and radiology. There are 136 pediatricians on staff at LGCMC. Allied health professionals include educators, nurses, nutritionists, occupational, physical, and speech therapists, psychologists, and social workers. LGCMC houses a 6 bed pediatric intensive care unit, with most recent data showing 550 yearly admissions. It also houses a 36 bed neonatal intensive care unit, providing care for the most critically ill newborns in the area, with yearly admissions. In addition, LGCMC offers many subspecialty, out-patient pediatric clinics, both at the hospital and in several outlying communities. Also, in October, 1988 LGCMC received an Illinois State Board of Education three year, one million dollar grant to augment and provide medical input to existing community programs in

surrounding counties, and in several rural, southern Illinois counties, in order to provide diagnostic services to children 0-3. In summary, LGQMC provides extensive services to children with complex medical needs.

Pediatrics Bioethics Committee

The Lutheran General Hospital Pediatrics Bioethics Committee was established in October of 1984, in response to the revised "Baby Doe" regulation, the Child Abuse Amendments of 1984, and the endorsement of the establishment of such committees by the American Academy of Pediatrics. This HEC was initially established as the Infant Care Review Committee, with consideration restricted to medical care of infants. However, in June, 1986 this HEC expanded its jurisdiction to include all pediatric patients cared for at LGH, ages birth to 18; the committee was renamed the "Pediatrics Bioethics Committee" (PBC). In July, 1987 this HEC once again expanded its jurisdiction, to include situations involving pregnant women and viable fetuses.

The PBC has published a manual of policies and procedures for case review, most recently approved on July 22, 1988. The purposes and roles of the PBC at Lutheran General Hospital are delineated as follows: (1) development and implementation of standards, policies, and procedures designed to protect the rights of minors; (2) to serve as a forum for discussion and analysis of complex individual pediatric cases involving withholding or withdrawing life-sustaining medical or surgical interventions; (3) to serve as a forum for discussion and analysis of the complex ethical issues that can arise in the care of the pregnant woman and the viable fetus and the development of policies which protect the rights of pregnant women and fetuses; (4) to serve an educational function including the development of an information base to be shared with families of critically ill and handicapped infants regarding

community resources for the continuing care of such infants and their families, including information about parent support groups, early intervention programs, relevant state and federal laws and regulations regarding the handicapped child and their family; and (5) to serve as a forum for evaluation of the quality of care, towards the goal of reduction of morbidity and mortality.

The Policies and Procedures Manual (1988) specifies that membership on the committee is to be "both representational and multidisciplinary." The committee membership is further delineated, as follows: four (4) medical staff representatives with one from each of the following Divisions--- Pediatrics, Neonatology, Obstetrics and Gynecology (OB/GYN), and one from outside Pediatrics and OB/GYN; the chairpersons from the Divisions of Pediatrics and OB/GYN are considered ex-officio members. Pastoral Care and Social Work each have one (1) representative. Three (3) representatives are included from Nursing, with one from each of the following areas---the Newborn Intensive Care Unit, Pediatric Nursing, and Obstetric Nursing. Two (2) residents of the community are also members, with one (1) of the community representatives a disabled person, or a parent or sibling of a disabled person, or a representative of a disability group and one (1) community member at large. One (1) hospital attorney is a member. If possible, a hospital staff medical ethicist is a representative. In addition, one (1) hospital administrator for the Division of Pediatrics and one (1) member of the Board of Directors are representatives on the PBC. Members serve four (4) year terms and participate on at least one subcommittee (Education/Resource Identification; Retrospective Review; or Policy Review and Development). The member or their appointed alternate must attend not less than sixty percent (60%) of the regular Committee meetings each year.

Regular meetings occur not less than quarterly. Additionally meetings designated as prospective review meetings are mandatory prior to undertaking a particular course of treatment, in all of the following cases where: (1) a proposed course of treatment of a patient involves the withholding or withdrawing of life-sustaining medical or surgical treatment; (2) a proposed course of treatment involves the withholding or withdrawal of "medically indicated treatment;" or (3) there is unresolved disagreement involving the course of treatment for a pediatric patient; and (4) when a hospital administrator receives a report from the Division of Children and Family Services alleging medical neglect of a hospitalized infant. The only cases exempt from a mandatory prospective review are those cases where the condition of the viable fetus or infant is judged by health-care providers to be incompatible with life. Attendance at prospective review meetings is mandatory; besides attendance by committee members or alternates, all individuals involved with the patient are included. Some prospective review meetings are considered expedited meetings, because of the critical condition of the child, and in these cases where it is impractical to convene the meeting in a timely fashion, the review is conducted without full membership attendance. Additionally there are cases which arise wherein a review is not mandated by the nature of the patient's condition or the proposed course of treatment, where, in a voluntary context, parents or health-care providers desire a forum for discussion; meetings called in this context are considered discretionary review meetings.

As stated by the Procedures and Policy Manual (1988), the primary goals of the prospective review committee meeting are the "identification and sharing of available facts regarding the patient's condition, the range of treatment options including risks, benefits, prognosis, and other information, as

appropriate. . . . The PBC should not be viewed as a decisionmaking body. Its primary role is to provide consultation and to review the decisions of those who have primary responsibility as decisionmakers, e.g., the patient, the patient's physician(s), nurse(s), parent(s)/guardian(s)."

In cases where all individuals involved with the patient are in agreement with the treatment plan, the role of the PBC is "to review the decisionmaking process to assure that appropriate consideration was given to the patient's interests." In some cases a physician or nurse member of the PBC will be designated an advocate for the patient and will "seek to ensure that all considerations in favor of the continued provision of life-sustaining medical or surgical treatment are evaluated and considered by the PBC."

In those cases where the PBC determines, after case review, that the course of treatment is contrary to the best interests of the patient, this information is communicated to the patient's physician(s) and parent(s)/guardian(s). If this disagreement cannot be resolved, the PBC will recommend to the hospital Board of Directors that the case be referred to the child protection agency and treatment will continue pending intervention by the agency or court. However, it is the intention that the PBC, by serving as a forum for review and consultation, render the need for Board of Director and court intervention a rare occurrence.

Besides cases reviewed prospectively, the Sub-Committee for Retrospective Review shall review all cases exempt from mandatory review and those cases which have received expedited review. In addition, a representative sample of cases involving pediatric patient death shall be selected randomly and reviewed to ensure that all appropriate cases are being referred to the PBC prior to patient death.

The extent to which HECs can achieve the goal of assuring that appropriate

medical treatment is available to critically-ill patients is summarized by Sister Corrine Bayley, vice-president for bioethics, St. Joseph Health System, Orange, California, and editorial advisor for the Hospital Ethics periodical (1986, p. 5):

I am convinced that the real success of ethics committees in our time will depend in large measure on the extent to which individual committee members experience the committee as a forum where they can test out uncertainties, hunches, and insights, where they can challenge one another, and where they can reflect critically with others on patterns of behavior and practice—in short, where they can experience growth in their own lives and be a life-giving force within the institution.

Biomedical Technology:

Complicating the Practice of Right Acting on Behalf of the Pediatric Patient

Advances in biomedical technology have rendered the question of right acting on behalf of the pediatric patient a complicated situation. The following five topics will be presented: (1) withholding vs. withdrawing treatment; (2) experimental therapy; (3) brain death in infants; (4) technology and the prolongation of dying; and (5) infant donors.

Withholding vs. Withdrawing Treatment

There is an essential difference between withholding and withdrawing treatment. Withholding treatment implies that a treatment is considered but not provided; withdrawing treatment implies that treatment in process is discontinued. If disagreement exists regarding the benefits of the treatment, serious consideration should be given to initiating (rather than withholding the treatment) as treatment provided can be discontinued

at a later time, however, the patient's condition may worsen while treatment is under consideration and withheld, thereby rendering it impossible to provide the treatment.

Experimental Therapy

Experimental therapy is welcomed by many patients, and recommended by many health care providers. However, there is a growing consensus of opinion that all that is required is medically established treatment. Therefore no individual should be coerced to provide or receive experimental therapy.

Brain Death in Children

Non-medical individuals have a tendency to think of death in "either/or" terms---the patient is either dead or alive. However, determination of death is a clinical decision, aided by examination and laboratory findings. Determination of death, for adults, is made for "the individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brainstem" (1981).

However, certainty regarding irreversibility and cessation of brain function is difficult to establish in infants and young children. The term newborn (38 weeks) is difficult to assess during the first seven days after neurological insult because of "difficulties in clinical assessment, determination of proximate cause of coma, and uncertainty concerning the validity of laboratory test results" (Report of Special Task Force for the Determination of Brain Death in Children, 1987, p. 587). These difficulties are reportedly accentuated in the preterm infant. In young children determination of death is difficult to make because there is controversy regarding the plasticity of the child's

brain's, e.g., the ability of the child's brain to resist insults leading to death. Therefore the Task Force for the Determination of Brain Death in Children (1987) published extensive guidelines describing recommended criteria for physical examination, observation periods according to age, and laboratory testing in order to avoid a false diagnosis of brain death.

Experimental Technology

Biomedical technology has recently advanced so that it can sustain or prolong life in a patient, who, without the benefit of the technology, would die imminently. Sometimes medical professionals will describe the person as trying to die against the technology. The infant and child cannot refuse life-sustaining treatments. Sensitivity is required, on the part of the medical-care provider, to ensure that the child does not have to die against the technology.

Infant Organ Donors

Each year in the United States there are reportedly 1000-1500 infants born who would benefit from organ transplantation, if the organs were available. Otherwise, without transplantation, these neurologically intact infants are doomed to death. Availability of organs is limited and many of the organs available are unsatisfactory for transplantation due to anoxic injury to the organs secondary to the cause of death.

Recently the use of donor organs from infants born with anencephaly has been considered for transplantation. Anencephaly is a severe brain malformation, incompatible with life; in fact, many infants presenting with anencephaly are still-born or products of spontaneous abortions. Live-born infants presenting with anencephaly may sustain brain function for several days after birth, later succumbing to brain death secondary to progressive respiratory failure. In order to maintain the organs in a

viable condition, the child must be placed on a ventilator.

The ethical question becomes whether it is appropriate to place a child on a ventilator, considered an invasion technique, not for the benefit of the patient, but in order to harvest the patient's organs for the benefit of another child. While Coulter (1988) concluded that the ventilator would not represent an onerous burden for the infant relative to the greater good that would be provided, harvesting of organs from anencephalics has been discontinued at this time.

Pre-Service Training for Special Educators

In order to increase the awareness of the issues presented to the HEC and to better assist families, the following suggestions are recommended in the training of early interventionists and other professionals in the field of special education. First, students in special education programs should observe the HEC to familiarize themselves with the questions that the infant and/or child with severe handicaps may pose to the professionals and parents. Credit can be given for observations as part of the requirements of a pre-clinical practicum. Second, some pre-clinical practicum hours can be credited for providing respite care to families of infants and children with severe handicaps. The requirement would help families, while increasing students' knowledge and understanding of family concerns related to caring for children with severe handicaps. Third, there needs to be a commitment by special educators to assist families by focusing on family strengths and coping resources. In order to do this, the educators need to learn how to interview families and administer appropriate inventories of family needs and strengths in order to identify family styles and formal and informal support systems. Fourth, it is essential for special educators to be

able to disseminate information about the intervention services available under the mandate of P.L. 99-457 and P.L. 94-142. In this dissemination, information can be provided to families and professionals about the potential of people with handicapping conditions. Fifth, university training programs in special education, especially those that prepare personnel to work with persons with severe handicaps, need to include knowledge of the issues involved in euthanasia as part of their instructional competencies. The Association for Persons with Severe Handicaps (TASH) can be of assistance by offering a training module in this area. Sixth, coursework is recommended which develops familiarity with significant medical vocabulary and condition and emphasizes teamwork skills necessary in working with parents and health professionals. Seventh, special educators in training should be encouraged to learn about and support state and national legislation that increases services and financial support to families of infants and children with severe handicaps.

In conclusion, the need for understanding some of the issues that are discussed by the HEC as well as the possible role of being an observer or participant on this committee may be evolving for the special educator as a result of recent advances in biomedical technology and as a result of P.L. 94-457. Persons in the field of special education have a responsibility to be aware of the issues.

Case Histories

The following case histories are presented for careful consideration by the reader. It is likely to render opaque or gray, the black and white positions the reader may have initially assumed on the issues presented in this paper.

Case #1

This case involves a 20 month old child in a persistent vegetative state (PVS). This neurologically intact child was born with a fetal condition which necessitated an organ transplantation. The child survived the transplant surgery but developed an infection status post the transplant with resulting seizures and a cardiac arrest, with the child now in a PVS.

The current status of the child is as follows: in the PVS, the child is doing well nutritionally, without evidence of rejection of the transplanted organ; the infection is now under control. There is a "do not resuscitate" (DNR) order authorized by parents.

The question posed to the HEC is whether to withdraw current steroid therapies; these therapies are provided to prevent rejection of the transplanted organ.

The issue regarding withdrawal of therapies involves parental concerns that the child will suffer when the transplanted organ is rejected, similar to the suffering they observed their previously neurologically intact child experience prior to transplant when the child's own organ was malfunctioning.

The course of the HEC review is as follows:

(1) The parents were advised of the existence of the HEC as an "open-forum;" the parents requested that their child's course be discussed.

(2) Prior to the full committee discretionary review, the Chairperson of the committee met twice with the parents.

(3) The case was presented to the HEC by the resident; attending physicians discussed the case and answered questions posed by HEC.

(4) The parents joined the meeting and expressed their concerns.

(5) The physicians described the likely course of medical events for the duration of the child's life, in the event that the parents agreed to the reduction or withdrawal of the medicine preventing organ rejection. The physicians attempted to assure the family that the child would not suffer and that there would be no comparison to the suffering the child experienced pretransplant. It was anticipated, by the physicians, that death would occur within 2-6 months with this course of treatment.

(6) The parents asked the individual HEC members, "What would you do if this were your child?"

(7) Response of HEC: several individuals reinforced that this decision was their's and one, which only they, the parents, could decide; HEC members redelineated the role of the HEC, as a forum for discussion rather than a decision making body.

(8) The parents exited the meeting.

(9) In the executive session of the HEC, it was the consensus of the members that the physicians plan to withdraw the rejection prevention medication was not against the best interests of the child, but that withdrawal of medication should not occur at this time because the parents were not ready to make this decision.

Case #2

This case involves a baby born at an outlying hospital, transferred to the tertiary care hospital because of multiple congenital anomalies, including cleft lip and palate, omphalocele, and an imperforate anus. On admission the baby had blood tests for chromosomes (negative) and omphalocele repair, as well as a colostomy. Status post surgeries, infant was stable on a ventilator and weaned from the ventilator at 3

days of age. The parents were encouraged by the baby's progress and the extended family visited the child. At 5 days of age, the infant began to have rapid respirations, cyanosis and signs of impending cardiac failure; a bedside echocardiogram was performed and revealed severe aortic stenosis and a ventriculoseptal defect. The infant then arrested and began experiencing seizures; the baby was reintubated and placed on a ventilator. A renal ultrasound, performed because of the presence of multiple congenital anomalies, revealed a single and malformed kidney.

The current status is that the baby is ventilator dependent and continues to deteriorate on ventilatory support. The baby is likely to have sustained some cerebral insult secondary to the episode on day 5 of life, though the extent is unknown. The seizures are now controlled with anticonvulsants. The surgeons describe high risk cardiac surgery as the baby's only chance for survival; the surgeons indicate that the quality of survival, post-operative, is unknown. However, the surgeons are certain that the child could die at any time if the surgery is not performed.

The question in this case is whether or not the cardiac surgery should be performed?

The issue in this case is disagreement between the medical care providers and the parents. The physicians and nurses know that the surgery is the child's only chance for survival. The parents wish to decline surgery.

The course of HEC Review is as follows:

(1) The chairperson meets with the physicians, nurses, and parents separately.

(2) An expedited HEC review is called.

(3) The surgeons present their case for performing surgery based on other children with similar cardiac abnormalities.

(4) The geneticists indicate that they have confirmed that this child does not have a chromosomal abnormality and no known syndrome; therefore the geneticists indicate that they are unable to describe developmental outcome based on a clinical diagnosis.

(5) The neurologists describe the child as hypotonic secondary to the arrest, with no focal findings; seizures are now controlled; the EEG is abnormal; and the patient is responsive to pain.

(6) The nephrologists indicate that at the present time there is insufficient information, but the possibility of chronic renal insufficiency exists, which would require long-term peritoneal dialysis.

(7) The parents are invited into the HEC meeting. The parents describe the pain they have experienced---first coming to terms with their child's physical anomalies, then encouraged by the success of the operations, only to witness their child's cardiac arrest and technology dependent, painful course. The parents explain that there are 3 other children in the family; parents describe earnings at the poverty level for a family of 5. Parents feel that if the child survives they will have to make her a ward of the state.

(8) The parents were dismissed and an executive session of the expedited review committee was held.

(9) Parents were advised by HEC that the prognoses for their child's neurologic and renal function are unknown; furthermore it was explained that the child does not meet criteria for brain death in children. Each of the individual anomalies appear to be treatable. Therefore it was explained that to withhold treatment (cardiac surgery) could not be

considered in the best interests of the child.

The Chairmen of the Department of Pediatrics reinforced that the hospital is obliged to act in the interests of the patient, which, in this case, is the child.

The outcome of the case was as follows: the parents continued to refuse surgery. The Board of Directors of the hospital contact the child protection agency of the state to request that they take protective custody. With this action pending, the parents consented to surgery. The baby died during cardiac surgery.

Case #3

This case involves a child transferred to a level III neonatal intensive care unit at 3 hours of age because of perinatal asphyxia and severe hypotonia. The diagnosis of Werdnig-Hoffman disease was made by the attending neurologist. Werdnig-Hoffman is a fatal condition involving the peripheral nerves to all voluntary and involuntary muscles; this child was unable to initiate any voluntary movement of his muscles with exception of movement of eyes. Of particular significance is this child's inability to move his chest wall and diaphragm adequately to maintain oxygenation and ventilation. Beginning at 3 weeks of age parents are approached by primary neonatologists regarding the infant's fatal condition and the possibility of withdrawing ventilator support. Parents are uniformly opposed to this suggestion.

The current status is that the baby is 2 1/2 months of age infant, ventilator dependent, on IV nutrition, gaining weight, tracking 180 degrees, demonstrating upward gaze and apparent recognition of primary care nurses. The primary nurses who continue to care for this baby are becoming increasingly emotionally distraught about prolonging the child's

life. The primary care nurses request a HEC review.

The question in this case is whether this child, with a fatal disease and inability to maintain himself off the ventilator, should be weaned from the ventilator in order to quicken the child's demise.

The course of the HEC Review is as follows:

(1) Prior to the HEC Review, the Chairperson meets individually with the parents, nurses, and physicians involved in this case.

(2) A discretionary HEC Review meeting is called.

(3) The head nurse describes the impact on her staff resulting from caring for this child.

(4) The neurologist describes the fatal condition; the neurologist predicts that on the ventilator this baby could survive up to 3 years, but the status of the child's condition would not change.

(5) The neonatologist explains that the child would die within hours after being weaned from the ventilator; the neonatologist could not definitively rule out the child's suffering before dying, once off the ventilator.

(6) The parents are invited into the meeting. The Chairperson summarized the information presented to the HEC; all this information had been given to the parents many times by attendings in the NICU and by the NICU social worker and pastoral care staff. Parents remain adamant about refusing to withdraw the treatment of the ventilator.

(7) The HEC meets and the consensus of HEC is that parents wishes are to be respected; while the child has a fatal condition and death is imminent, the child does not currently meet criteria for brain dead. The child will continue to be cared for in the NICU with the social worker helping the family investigate alternative long term care placements,

which will provide sophisticated medical care. Counseling will be provided to the primary care nurses to help them cope with their emotions as they care for this child.

Case #4

This case involves a neurologically intact 2 1/2 year old child resuscitated by paramedics after being submerged for 15 minutes in the family backyard pool. The child has been in a coma for 3 months; he is ventilator dependent and totally unresponsive.

The current status is that there has been no change in neurologic functioning since hospitalization. The mother is in her 8th month of her 3rd pregnancy; the patient's older sibling, age 4 1/2, is at home and is demonstrating significantly regressed behaviors and language since the sibling's accident. Recently the attending physicians and the child's pediatrician have begun to discuss, with the family, the possibility of withdrawing ventilator support for the child.

The question in this case is whether this child should be weaned from the ventilator. Parents are suffering the loss of their once normal child and very uncertain whether or not to continue life-support. Parents request an HEC review.

The issues in this case include the extent to which the assumption can be made regarding irreversible brain damage, as well as family issues including the forthcoming birth of a third child to this family, and the emotional difficulties the second child is experiencing related to the turmoil the family faces related to the patient's condition and the experience of the extended intensive care hospitalization.

The course of the HEC Review is as follows:

- (1) The Chairperson has developed a relationship with this family, as

have the attendings and nurses. Parents request that their child's condition be presented to the HEC so that they can rely upon the HEC as a forum to help them understand the decision they, the parents, face. A discretionary HEC review is called.

(2) The child's case is presented by the pediatric resident.

(3) The child's community pediatrician provides background information on the family and describes them as exemplary parents with a supportive extended family.

(4) The family therapist, who has worked with the family since the accident, describes the effects this situation is having on the sibling and how the mother's emotional reactions are additionally stressed by the impending birth of her third child.

(5) The parents are invited into the HEC meeting and they discuss their family, and their experience of unrelenting guilt and grief. Parents request information on prognosis.

(6) The neurologist indicates that it is unlikely that the child will regain consciousness. In the unlikely event that the child regains consciousness, the neurologist predicts that the child will be significantly impaired, stressing that the child will be very different from the child she was prior to the drowning.

(7) The parents indicate that they do not feel prepared to withdraw treatment and instead request additional time to make the decision, indicating that they understand that they are not being hurried and that they will probably wait to make their decision until a few months after their baby is born.

(8) The HEC meets and the consensus is for full support for the parents' decision. This is shared with the parents.

The outcome of the case is as follows. A third child was born to this family 3 weeks after the HEC review. Eight weeks after the review this child regained consciousness (5 months after the accident). Neurological findings include spastic quadriplegia, with severe visual and hearing impairment; cognitive functioning is difficult to determine but the child does not appear to understand language or recognize members of her family. This once normal, now severely handicapped child, for whom withdrawal of ventilator support was considered, is involved in assessments so that a case study can be completed; it is anticipated that the child will be enrolled in the local early childhood special education program. The older sibling is preparing to enter kindergarten and continues to demonstrate significantly regressed behaviors and language and so a case study is also being completed on this child so that support can be provided by the school district.

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